

Roundtable Discussion with Three Panels

So what we actually need to do as a committee now is to look at where do we want to go, what steps do we want to take after having heard some of this information. We have heard already some particulars that have been brought up, some particular recommendations, one being that we have another letter from our new chair to the Secretary describing some of the information that we've heard today, broadening the aspect of discrimination.

The second is, again, do we want to specifically invite again the Chamber of Commerce to address some of the questions that our committee has?

Third is to make a specific request to the Department of Justice to review some of the gaps in the legislation as we currently have as to whether we need to go any further with this. Would new legislation then cover those gaps?

The other that was actually one of the purposes of this particular committee was to look not only at the current genetic tests and genetic diseases as we know them today, but the broader aspect of genetics and genomics as to where we're going to be going in terms of research and medical services. So I think that's another area to look at.

We'll begin first with Debra, and then Reed.

DR. LEONARD: I think from the presentations today, it's clear that fear of genetic discrimination is real and it's prevalent. It is not rare. This is fear of loss of insurance as well as employment, and not only for themselves but down to the next generations. Real discrimination probably has occurred but may not be realized to the full extent because of this fear. People are not having the testing, so there may not be as much actual discrimination occurring as might occur if people were having the testing.

This fear is compromising medical care, diagnosis, defining risk, treatment after testing, and realizing possible benefits for other family members. It's also compromising research participation, and it's most disturbingly compromising life and death decisions by patients and people. Health insurers look like they are supporting laws to protect individuals from genetic discrimination, and I guess employers are not going to impede laws for genetic discrimination, but I think it's also clear from Jane's presentation that federal laws protecting against genetic discrimination do not exist, not that provide adequate protection. So I don't know that asking for a reiteration of that from the Department of Justice is really worthwhile.

SACGHS has already agreed that legislation is needed. We've sent two letters to the Secretary, and so far the House is not moving forward. I don't know if they are deliberating on, but they are certainly not passing legislation. I am loathe to continue our previous pattern of sending letters to the Secretary since this appears to have had little impact on achieving passage of genetic discrimination protection laws.

So my question is what else can we do? Can we send information from this public forum to members of the House or to the Secretary to ask him to pass on? I guess the only thing we can do is address the Secretary. Can we request members of the House to address SACGHS, chairs of the committees that are deliberating this process? Is there anything else we can do other than simply sending letters? Because that has not been very effective, in my opinion, to date.

DR. TUCKSON: Let's just get a quick response in terms of some of the technical issues there.

On the first part of your comment, we are not allowed -- I'll get corrected, I'm sure, here in a second, but we're not allowed to directly write to the Congress. What we can do is to ask the Secretary to take our information and send that to Congress. So instead of sending the letter to the Secretary, you can ask the Secretary to send stuff on our behalf to Congress.

As regards inviting members of Congress to come here and be a part of a discussion, that's one I'm not sure about.

MS. CARR: Well, you know, we have invited congressional staff in the past, and I don't think there's a prohibition in inviting a member of Congress to come and talk to us. We could certainly check with the Secretary's office about that and convey a letter of invitation.

DR. McCABE: My point in asking the Secretary to communicate with the Justice was to broaden the discussion, perhaps, within the administrative branch. So that was really the intent, because I agree with you, it's been very frustrating the efforts that we've made and have not moved forward. So that would be also, perhaps, when I asked Vahid Majidi the question before, and I apologize for not providing some pre-question information to him, but that was really the intent. So perhaps we could discuss are there other things that we could do to increase the visibility of this issue within the administration?

The President is on record as being supportive of this, both before he became President and during his presidency. Secretary Thompson similarly is on record, both as a governor and now as a Secretary, being supportive of this. Yet there has been no movement. Part of my reason to challenge the Chamber of Commerce to come before us is that the scuttlebutt that I have heard is that the Chamber has been very active in holding this at the desk, that they are really the people -- and I appreciate Mr. Aitken being sent to represent that segment of our economy, when the people sending him didn't have the guts to come before us themselves.

So I appreciate your willingness to do that, Mr. Aitken. I think you should take back the message, though, that we see what was done. We're not stupid, and you were sent here so that we could not question the people who are holding this at the desk. That's what we have to do is figure out how we can mobilize all of what we've heard today. Dr. Hudson said that this is a major issue throughout the United States. How do we mobilize the people of this country to counteract the Chambers' efforts to subvert what is right for the American people?

DR. TUCKSON: The next person on the list is Emily. But just for factual information, Mr. Aitken, can we be clear from you whether or not -- you represent through our association, or the coalition -- and I need you to clarify whether it's an association or a coalition, of which the Chamber is a part. Can you give us a sense of how many other organizations are there that have the same opinion or philosophy that you've expressed so we'll know whether or not, as Ed really lays it out here, how much of this is the Chamber, but how much are also other interests here?

MR. AITKEN: The Chamber is a member of the Gene Coalition. SHRM is a member of the Gene Coalition. I would guess there are some 40 other associations that are members of the Gene Coalition. The principles that I laid out are principles that have been adopted by the Gene Coalition, which the Chamber is a part of. I don't recall, and I certainly don't want to speak on behalf of the Chamber, that the Chamber has ever said no, they're opposed to a bill prohibiting genetic discrimination. They have raised concerns within 1053 and have shared those concerns with public policy decisionmakers on both sides of the aisle, as has SHRM. Again, I don't want to speak for SHRM, but the Coalition has been very consistent on those set of principles, and that's looking at any legislation that's moving through, whether it was advanced in the House or

the Senate.

DR. TUCKSON: As we turn to Emily, Mike, you've been very forthcoming here. I wonder whether -- and I know you've got staff support here as well, or other colleagues -- if we might get a list of those other 40, and our team can try to, during the lunch break or sometime today, get that back so at least we'll understand the range and depth of the interests that you are so articulately representing today.

Emily?

DR. WINN-DEEN: So I guess what I'd like to understand while we have you on the hot seat here right now is what exactly it is that employers are concerned about? Because it seems to me that from an administrative point of view, for a company that has employees in more than one state, that having a federal piece of legislation covering this would actually simplify their lives in many ways, rather than having to worry about the sales rep in New Jersey having a different situation than the sales rep in Tennessee or Texas or California or whatever. So even if you don't have multiple headquarters in different states, many companies have employees distributed over all the states. So is it just the particular wording? What is the issue with having a sort of unified floor?

MR. AITKEN: Well, S. 1053 is not a preemption. It's in addition to whatever the state laws are, so there's a difference. If it was a preemption, I don't think there'd be as big a concern with 1053.

DR. WINN-DEEN: I guess my understanding was that if it was in a state where it was a higher level than the state, that the federal law would then apply. So the only places where the federal law wouldn't apply would be in states that have even higher levels of protection. Is that correct?

MR. AITKEN: Correct. But that could be quite a few. I don't have the information in front of me, but there could be several, and that could --

DR. WINN-DEEN: Do you know? If 1053 went to becoming law, how many states would have stricter regulations?

DR. LICATA: If you give me about five minutes, I can tell you, because I have a complete analysis of all the states. So I'll work on that right now.

MS. MASNY: Heidi Williams.

MS. WILLIAMS: Yes, thank you. There are a couple of points that I wanted to make personally. First off, my children are the ultimate irony as far as health care insurance is concerned, because Humana, Inc. is headquartered in Kentucky, in Louisville, Kentucky. My children were born in the State of Kentucky, and yet they were denied twice in writing, and the Genetic Alliance has copies of these letters, due to their carrier status. That was the only reason they were denied.

Also, I want to make this point, that alone in my family history -- and there is a history of obesity, diabetes, heart disease, stroke, prostate cancer, breast cancer, and my personal favorite, male pattern baldness. These are all considered genetic disorders under the genetic disorders website at NIH, every single one of them. What I am afraid of is that once employers and insurance companies get tired of picking at the more exotic disorders, that they're going to come after people's family histories, where these things have been showing up year after year after year, generation after generation.

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I'm all for education, too, as far as these disorders are concerned. I think this is just as important as the legislation, because I know that somewhere down the line my children are going to have to have their spouses genetically tested to see whether or not they carry the AAT gene, because this will go on to their children possibly, ending up as a symptomatic patient just like myself if they are not tested.

So this could come down to even their children as they are born, or even before they're born, in the womb, and they could be prevented from employment or insurance.

DR. TUCKSON: Thank you very much for that. That's very helpful.

We have Debra, and then Cindy, and then Francis.

Let me just try to caution everybody and just do a time check here. We've got a tough challenge of a 1:05 time we were supposed to stop, break at 1:05, but we can maybe move it a little bit. Did we change the schedule? We've got a new schedule, but even then we've got a tough challenge. This is great, between yesterday and today. This is terrific. But it's 1:15.

So the bottom line of what I'm trying to get at is we're trying now to take this and zero in on what this committee can do. So I want to just keep people on point to what can we do and what should we do.

Debra, let's go there.

DR. LEONARD: Just a quick follow-up question to Mr. Aitken. I might have missed it. What is the Gene Coalition? What is their mission? What actions have they taken to date?

MR. AITKEN: The Gene Coalition is a group of organizations, principally employer organizations that have been involved -- there are some health care organizations that are active, as I recall -- that have worked with both the House and Senate on legislative proposals dealing with genetic discrimination.

DR. TUCKSON: Cynthia, and then Francis.

MS. BERRY: It probably goes without saying, but I'll say it again anyway. I think it's unanimous on this committee that we all strongly support federal legislation to prevent genetic discrimination. But I've also been in Washington long enough to know that sometimes we have a tendency to say to someone, well, if you disagree with me or you have a different approach, you're bad or you're evil or you have nefarious purposes, when really that's not the case.

I think everyone in this room has similar purposes, and the people that we heard from earlier on the first panel were telling us compelling stories about their personal lives, their health, their livelihoods, their families. Folks on the other side of the issue, though, are probably doing similar things and they're focused on their livelihood and their ability to stay in business. I don't want to demonize one side or another, except what I'm thinking in terms of what we can do as a committee to help facilitate some sort of positive action is see their common ground.

I know that individuals have been trying and working on this issue, but just for the sake of throwing something somewhat controversial out there, I haven't seen, Mike, the specific proposals that the Coalition may be putting forward or is advocating with regard to changes that need to be made to the Senate bill, but if you've got actual legislative language, it might be

helpful for us to look at that.

To throw out the little controversial piece is to say to the rest of the folks here, and I'm not saying I agree with them because I haven't seen the proposals, but just for the sake of argument, if we had the recommendations of that coalition, is a bill that incorporates those changes better than no bill at all? In other words, if we were to say to the employers who were expressing some concern, or maybe some of them even oppose the legislation, if we were to adopt their recommendations, is the feeling that it would gut the legislation and not be worthwhile, or is it something that people could live with as a compromise? In other words, is it better to have a bill that's less than perfect, or do we fight for something that we feel is absolutely critical? Each and every one of the provisions as crafted by the Senate is integral to the actual legislation?

I throw that out there as just sort of a -- and it's hard probably for you folks to answer because you don't have the draft proposals or recommended changes in front of you either. But I wonder if that could be a starting point for what we might do as a committee.

DR. TUCKSON: Excellent point. We'll come back and nail that one.

Francis?

DR. COLLINS: So a suggestion, and then I want to ask a question.

The suggestion in terms of trying to influence the political process beyond what the committee has done already in terms of writing letters to the Secretary. I like the idea of encouraging the Secretary to follow up by contacting the relevant members of the legislative branch that are in the best position to actually get this unstuck, and in my view that would include the speaker, that would include the majority leader, Tom Delay, and it would very much include Joe Barton, who is the chairperson of the Energy and Commerce Committee, which is the committee that would have the primary jurisdiction over this bill. If Mr. Barton were to take an interest in holding a hearing on this, I'm sure that would be something that would happen.

So those are the three sort of pressure points that might be included in such an appeal to the Secretary to make good on what I believe is a very sincere effort on the part of the Secretary to see something happen here. We could perhaps push this just a little further by that explicit suggestion.

The question I wanted to ask, I didn't want to let the health insurance side of this completely off the hook. Somebody a little bit ago said, well, the health insurers are in favor of a bill that would prevent genetic discrimination. I'm not quite sure that that's the way I've heard it. So can I ask Dr. Armstrong, obviously your arguments are that health insurers have not been using genetic information and will not be interested in using it, yet we heard an example from Heidi Williams where her children almost lost their health insurance. But for the intervention of a reporter might very well have had that happen.

I think, frankly, all of the information we hear from the surveys that Dr. Hudson reported and from all of our distinguished panelists is that the public basically doesn't believe that. The public does not believe that health insurance companies are going to pass up the opportunity to use this information if they had the chance to do so. That's just not an argument that seems to be carrying the day.

In that situation, if it's true that health insurance companies are not interested in using the

information, then I would say they probably shouldn't care too much if there's some legislation that says they can't because, well, they weren't going to anyway. So does AHIP support S. 1053?

DR. ARMSTRONG: One, I would refer you to AHIP. I can speak from an Aetna perspective, only because I don't know the evolution of AHIP's thinking on it, although somebody in the audience is here from them, so they might address that. From an Aetna perspective, we have supported the Senate bill. Our perspective on the use of genetic data is that, in fact, it's already occurring. This activity has been happening in health plans for decades. We handle hundreds of thousands of genetic claims a year. In the health plan there's a tremendous amount of management programs that go around that involve disease management, pharmacy management. Some of it may not be identifiable as genomic activity now. In the future, it may be.

It may plug into chronic hypertension management, disease management, a whole host of other management conditions that are being actively managed, perhaps not under the rubric of genomics, but a few years down the line that will probably be the case. Our interest here is in having access to the data for our operations in our management programs but not to use in a discriminatory manner, and then I would further question about the evolution of AHIP's position on it, too.

DR. TUCKSON: Can we ask if there is a person from AHIP, can they come and let us know what the thinking is? I think, Francis, it's important to underscore what Joanne just said in the sense of the use of the information. I think for the record I'd like us to be precise. If I heard Joanne, using the information for the purpose of -- her whole testimony was around using information for appropriate coordination of care is something that you are very clearly interested in.

I think Francis, the thesis of his question, if I understood it, is the use of this information in ways that would be negative to the individual from an underwriting or insuring point of view. I think that Joanne's answer stands on its own. But I think this is a very subtle point that needs to be distinguished.

MR. WILDER: Thank you. My name is Tom Wilder. I'm the vice president for private market regulation with America's Health Insurance Plans.

We did not oppose the Senate bill. We have expressed to Congress on various occasions our concerns that legislation be very carefully drafted for some of the reasons that Joanne pointed out. There are a number of reasons why health plans use health information, as part of disease management, as part of other programs in communicating with a provider, in communicating with patients. We want to make very sure that if there is legislation that passes Congress, that it doesn't jeopardize those functions.

We would agree that you should not be able to use genetic information to unfairly discriminate against somebody, but we want to make sure that the information that the health plan has -- in fact, the health information the plans have been using for decades is not jeopardized.

DR. TUCKSON: Could you then extend that a little bit towards the real issue now, then, which is the bill in the House? Do you find that AHIP's position is one that is supportive of -- and again, you've probably got a better finger on this than I will, so I apologize for the general nature of the question. But is AHIP in support of trying to reach a consensus that gets this now through, or would it find itself more aligned perhaps with some of the positions that people are sort of associating with the Gene Coalition?

MR. WILDER: We are members of the Gene Coalition. Again, what we've tried to do in dealing with this issue is educate members of Congress about how health plans use health information. The bill that's on the House side, the Slaughter bill, to be honest with you I'm not familiar with all the details of that bill. I do know it's very different from what came over from the Senate in a number of respects. But again, if there is going to be federal legislation, our only concern is that some of the issues that Mike and others have raised are addressed in the bill.

DR. TUCKSON: If you can hang there for a second, let me turn to the other side of this, the equation, for a minute. NBCC -- and I think we sort of heard, I think in testimony earlier, that they sort of didn't like the Senate bill because it wasn't -- and maybe this is not a fair way to say it, but wasn't tough enough on some of the sanctions. So on one end we've got this Senate bill which is -- it's kind of strange to say it this way, but a middle ground sort of deal. Some people feel like the Senate bill has too much in terms of risk on the part of employers in terms of legislative sanctions and unintended legal exposure, which makes them nervous.

On the other hand, you've got some folks who are saying it isn't tough enough, and then you've got this sort of middle ground somewhere.

Do we understand anything or can we learn anything right now on the potential of fractionization on the side of the people that sort of want it more? I mean, are we going to see any bringing together of that part of the community, or are we going to see the NBCC staying way out and not coming into any chance of a grammar of coexistence on this?

MS. FISHER: Can I speak to that? I know something about the NBCC's position, and they are generally people who say that things like breast cancer would be cured if it were a man's disease. I think they've politicized the issue so much that they really are off to one side. I agree with Ms. Berry that this should not be a situation where someone becomes sinister and malevolent.

I do think that the stakeholders that you're asking about, those of us who do have a vested interest in getting this moved along, are not championed any longer because the National Partnership for Women and Families has basically lost our charge leader. She has since gone to a different organization. So there really isn't anyone who is still out there consolidating, still leading the charge for those of us who are still in it. I think that's a big problem.

I also think that it's difficult for your committee to approach Congress because of enjoinders against your lobbying activities. However, I would say, in echoing something Dr. Collins said, Secretary Thompson's wife, his mother-in-law and his daughter have all had pre-menopausal breast cancer. I think there's BRCA1 afoot. I think that those of us who are out there are waiting for him to speak formally on this issue, and I think he would go far toward getting it done.

DR. TUCKSON: One last question. So as we try, then, to see where the leverage points are for us to be able to do something meaningful, Mr. Aitken mentions a meeting that occurred a few months ago where it sounds like there was some sense of trying to get a consensus on the part of differing parties, and to date no response. I'm sure the other folks who didn't respond yet may have some view about that. But at the end of the day, is there anything that anyone here can tell us that is another meeting that is planned, any behind the scenes brokering to try to get this done, or from all available information at this point is this committee left to assume that this thing is basically fractionated, that parties are in separate camps and there is no work to try to pull this together? Can we know anything about the current status?

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Please state your name, please, and come to the mike.

MS. HOWES: My name is Joanne Howes, H-O-W-E-S. I'm with the firm DDB Bass & Howes, and have been working with the Coalition for Genetic Fairness that Becky Fisher referenced, half of the National Partnership for Women and Families.

I think the reality that many of us feel is that we worked very hard together. The bill that passed the Senate, they were changes made outside of the National Breast Cancer Coalition. Groups saw it. It was a compromise. It wasn't what everybody wanted, but we felt in good faith that that was the right way to go. We had been assured at that point in time that it had the support of the Chamber of Commerce, that it had the support of the health insurance industry, that they had been at the table, frankly, more than we had been at the table when those negotiations got made to move S. 1053.

So where we are now is that we've worked also very hard to get the attention of -- Phaedra here is in the speaker's district, and she has been working very hard to get the attention of the speaker. We've been working very hard to get the attention, as Dr. Collins said, of the people in Texas. I think that we feel very stymied.

DR. TUCKSON: Thank you for that. I think I can understand what you're saying there. But as of right now, I think what your answer is, though, is that we're unaware of any particular activity that is on the docket where everybody is sort of sitting down and trying to work this out, that there seems to be a great deal of frustration.

DR. COLLINS: There's an election in two weeks.

(Laughter.)

DR. COLLINS: Nothing is happening in this town if not election-related.

MS. HOWES: The message that we have heard from the Republican leadership is that they're not going to do it this year. They've said it publicly, they've said it privately at the House. They're not going to do it.

DR. TUCKSON: Thank you. Thank you very much.

We're going to start now mailing this through to solutions. But, Ed, you wanted to comment?

DR. McCABE: I just wanted to comment, first of all, about the election. But then I'm concerned that in the next session, that it will still be stuck at the desk. So the issue, and maybe Cindy, I think the issue is how do we pry it loose so that there can be the deliberation? As long as it's not under deliberation, then there is no discussion and it basically doesn't exist. So the issue is how do we pry it loose so there can be public discussion?

DR. TUCKSON: Phaedra has a comment.

MS. MALATEK: I just want to quickly comment on my conversations with the speaker's office. They had a ready answer. It's clearly something that is on his plate and something they have reviewed, and this was with the senior health policy advisor. So I felt like it was somebody who was in the know in terms of where the speaker sat on this.

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His comment was that we are not going to legislate something that's not happening. So they're looking for bodies, they're looking for casualties, and until they have those casualties, they're not willing to move forward on it. We're casualties, but I'm the only one here from the speaker's district. Perhaps it needs to come from the constituent level, I don't know. But they're not going to do it if it's not a problem at a constituent level is the message that I heard from the speaker.

DR. TUCKSON: Thank you.

Ed?

DR. McCABE: Well, that was the purpose of today's panels, because we've been hearing that it doesn't exist. But I can tell you as a medical genetics professional, it does exist, because I hear it over and over.

I think what we do is that we perhaps, as a way of preparing ourselves for the next round, I don't know if anybody has looked through this, but the testimony we heard this morning in the first panel was incredibly powerful. The documentation that we have in the spiral-bound book is incredibly powerful and suggests that it's still anecdotal, but it's an accumulating number of anecdotes. It's not something that can easily continue to be swept under the rug.

I would then propose, Reed, some discussion perhaps with you and Sarah over lunch about what it would take and whether there is staff time available to take this spiral-bound notebook and summarize it to send it forward.

DR. TUCKSON: That's a terrific suggestion. Let me try this, then, and I really have to see now what the committee wants to do. Let me propose -- and I'm going to miss something -- what I think I hear at least as next steps.

Number one, and this is the most minimal step, that we ask for a meeting with the Secretary of Health to tell to him about how serious an issue we think this is, that we would present to him a summary with detail of the testimony we heard here today, particularly the overwhelmingly powerful statements we heard from our public panel, as well as the scientific studies that we've heard from our health professional colleagues, so that we bang that somehow together in a document, as Ed I think has just suggested, that we can hand to him, and at the same time perhaps ask him if he might broker at that conversation a meeting with the Secretaries of Labor and of Commerce? Justice. Excuse me, I forgot. Justice.

We'd sort of ask them all to come together, and/or senior people, so that we can sort of give it all to them at one time to try to extend the nature of the conversation within the federal government. Of course, all this depended upon Francis' very important reality check about what happens in the next couple of weeks and so forth and so on.

That means, by the way, that whatever we come up with, we're going to want a conference call discussing next steps based on some of those realities.

DR. McCABE: I would point out that a very important thing has occurred. You mentioned it. Our charter has been continued to 2006. So no matter what happens, we continue.

DR. TUCKSON: Good point.

DR. McCABE: This issue will continue.

DR. TUCKSON: So maybe the strategy could be the same.

DR. McCABE: Yes. I think it's important for us to begin the strategy so that we can address this problem in the next session of Congress.

DR. TUCKSON: Number two, that as part of our asking for that meeting with the Secretary, that we would take the same document that we've already got bound together and we're going to work on, Sarah -- thank you -- would be that we would ask that that testimony be transmitted to the Congress as a function of what we do. Since we can't do it directly, we have to sort of say that we're so concerned about this that we've asked the Congress to -- we want to get it to them, and you're the only way we can do that, so please send it.

Number three. Francis indicates that whatever we do with Congress should be focused in on three major foci, number one being the speaker, number two being the majority leader, and number three being Joe Barton. What's that committee again?

DR. COLLINS: Energy and Commerce.

DR. TUCKSON: Energy and Commerce.

MS. BERRY: Also add Education in the Workforce. I believe that bill had been referred to three different committees in the House, so you'd want to --

DR. COLLINS: I think it's pretty clear that Energy and Commerce is the one everybody is looking at to take the lead. If you want to sort of make your effort most likely to yield fruit, instead of being too diffuse, I would go for Energy and Commerce.

MS. BERRY: Well, it's not a matter of being diffuse. You don't want the other chairmen to feel like they've been ignored or to give them some sort of excuse for saying, hey, I wasn't part of that deal, or I didn't get that stuff. So I would send it to the chairmen and ranking members of all of the three committees that have jurisdiction.

DR. COLLINS: Fine, but prioritize.

DR. TUCKSON: So friendly amendment, and I think that sounds like a winner.

You had a comment on this?

DR. WINN-DEEN: In looking through this book, what I don't see is actual copies of everyone's testimony that was given today. So it would be really good if we put all that testimony in, and also where people are from, what congressional district. City and state is extremely helpful because it brings home the fact that this is not just one Congressman's issue. This is an issue for all.

DR. TUCKSON: Good, and I think I see Ed's hand.

DR. McCABE: I just would say that as powerful as the comments were from the first panel, I would include the comments from all panels this morning. I think that would be important.

DR. TUCKSON: Yes, that's terrific.

The next thing I think that we hear is that we will send a letter to the Gene Coalition asking -- Cynthia's point, and you'll have to help me with the language on this later, Cynthia. But ultimately I think it is would you please be specific about what it is that is wrong with this legislation that you object to and what is the solution to this problem. I think it was Francis' point as well that was pretty clear on it. So if you guys are perceived as being the holdup here, then help us to solve the problem or declare for one and all, if that's how you feel, that this isn't a problem and we're going to stick to that and we're not changing. So just what is it? So we don't have to keep arguing with you about it, just tell us what it is.

Similarly, AHIP I think has a responsibility here because it's been asked specifically in the meeting to state where you are on it and how you view it. I think the issue specifically for AHIP is to be very clear about whether or not it is a problem of use of the information for coordinating care, that stuff which is -- and I'm going to, by the way, ask the people from the advocacy coalitions. I think our thinking on this would be greatly advanced if you have strong feelings about the use of the information for coordination of care, if you have a problem with even that part of it, we really all need to understand that.

But if it's your issue is really the discrimination issue around underwriting and insurance and so forth, that's one thing. But if somebody says, hey, you're not supposed to know it to even help coordinate care, which is all the testimony we heard from the Aetna representative, and that's what AHIP's point is, we need to know whether that's an issue or not. But I really think it's probably the other, and maybe I'm generalizing too much.

Yes, Ed?

DR. McCABE: Reed, I would ask also, I don't think that we can approach or you can approach the Chamber directly, but I would ask the colleagues at the Chamber of Commerce, given that I have demonized them here today, to respond because, as Cindy said, people in the room all understand that we have issues, but not being in the room raises serious questions. So I would ask friends of the Chamber to take back the message that perhaps they might want to respond in this packet as well.

DR. TUCKSON: Well, Ed, you have more experience at the helm than I do, will ever have I hope, but I think we are able to write a letter given that testimony has come up and offer them the opportunity to clarify. I think you're good. So we will also send a letter to the Chamber. But I would probably say, though, that given the number of organizations that I assume are in that coalition and the clout, the Chamber may be an issue but everybody in there is going to be important to our committee, and so we'd like to hear.

Lastly, I think that's my list, and I'm wondering what did we miss?

DR. FEETHAM: I would just recommend Dr. McCabe's point about we have cumulative anecdote, but we also, as you indicated, have all the speakers' testimony, but they also have publications with hard data, and I would strongly recommend that those data be part of this packet that you're compiling.

DR. TUCKSON: Thank you for that.

I guess the last point would be this, and that is I think what the committee is pretty clear about is that this issue has been prioritized. We as a committee have prioritized this. I would be surprised

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if there's anybody on this committee who feels less strongly today about this than they did before. I think we're probably pretty well jazzed up about this. So what I wonder, and I have no idea whether this is going to be appropriate or not, but we need to assess, and that is maybe at our next meeting consider bringing together those people that are determined, and if there's no negotiation or conversation happening outside of the room, put a little circle and invite people to it, and if you don't come, you get Ed McCabe.

(Laughter.)

DR. TUCKSON: So that should strike fear in everybody's heart. So we create a circle and we say, look, we're going to lock the door and we're going to have everybody work it out. I mean, if there's nobody else working it out, then maybe we have to try to work it out. I mean, that's not usually the kind of job that we would have, but in a vacuum maybe that's something we have to fill.

I want to conclude this with that clearly we need to talk about this again as a committee. It is very clear that we're going to need to probably have a conference call on this if we're going to get anything. So we're going to summarize all this, get it back to folks, probably do a quick call, not take a lot of your time but make sure that we're locked in on this as we go forward.

MS. DOMINGUEZ: I just wanted to offer an assistance to the Department of Justice, to have the Commission independently analyze the gaps there may be legislatively. We have a lot of experience in this area.

DR. TUCKSON: Great.

MS. DOMINGUEZ: So we'd like to do that.

DR. TUCKSON: That would be a very, very good addition.

We've got to go to lunch, but let me say one thing about the lunch. You all are not going to be happy, either the members of the committee or our guests, about lunch. It's short and it's a no-fun lunch break. It is not because we are rude. It is not because we don't love you or care about you. There are more laws and regulations that tell us whether or not you can have four people in a room with a sandwich that it will make your hair hurt.

I just have to tell you why there is a reason why this thing is set up the way it is, and it's not because we are rude. So if you don't like the fact that you all have to run and try to find a sandwich and be back here in 15 minutes and that it's a working lunch and that it's all scrunched up like this, it's the only way we can feed these people, to make them work during the time that they're actually eating. Otherwise, we couldn't even give them a hamburger. So it's not our fault, and I apologize for it, but that's just the way bureaucracy is.

Thank you all very much. See you in 15 minutes.